

Redesigning Care to Provide Value at End of Life



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Goals for Today

What is the problem?

High cost and poor outcomes in US health care – low value

What is value-based health care?

How should we assess value in advanced illness?

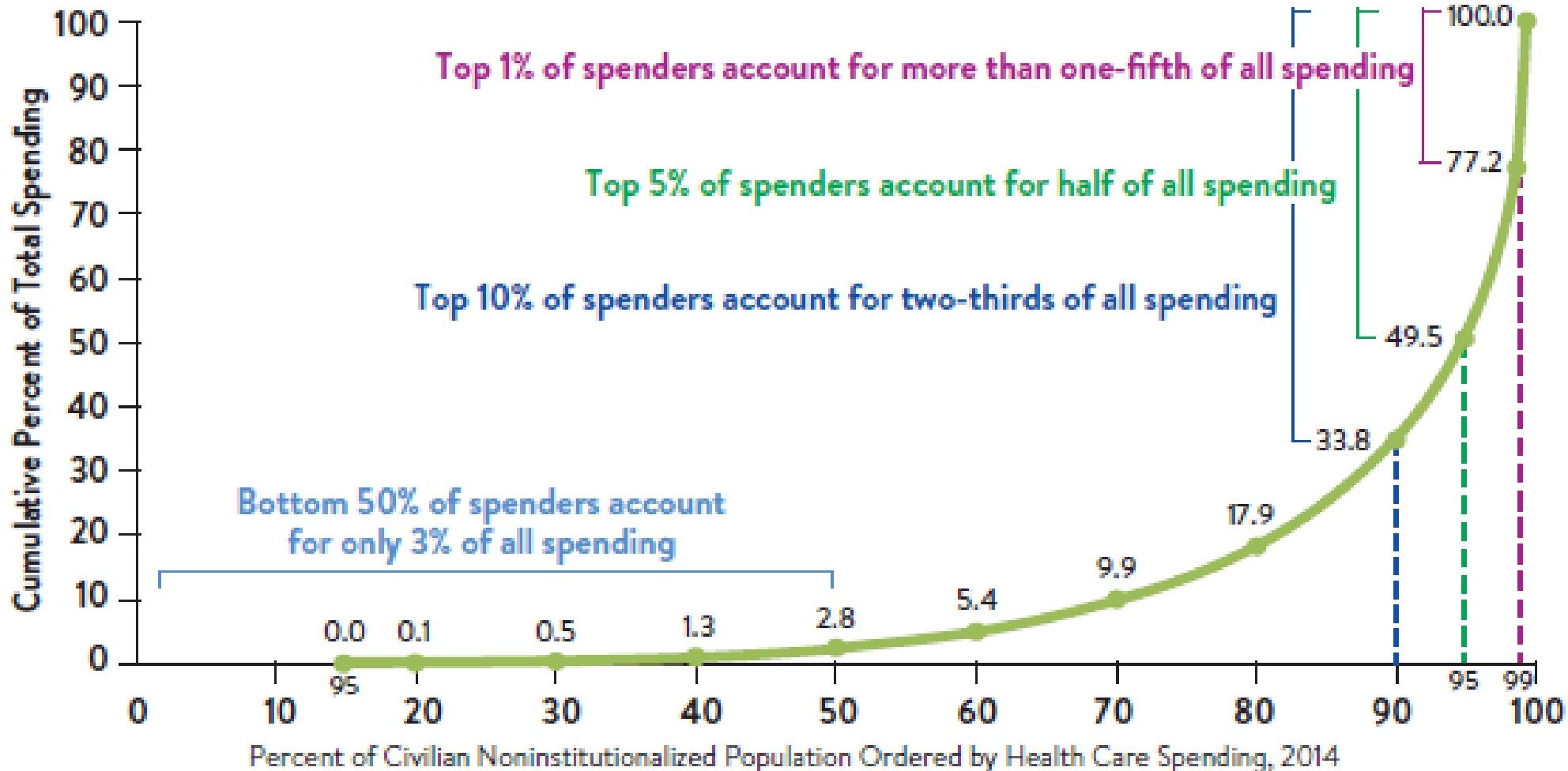
What needs to be done among the major influencers:

Public – patients and their families

Practitioners and administrators

Policy makers

High Needs Patients Account for the Majority of US Healthcare Spending



From: Dzau VJ, et al: JAMA 2017;317:1461-1470

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End of Life Care Contributes to High Health Care Spending

13% of all health care spending goes to care for people in their last year of life

25% of Medicare spending goes to care for people in their last year of life

32% of CMS spending goes to individuals with chronic illnesses in last two years of life

78% of CMS spending on cancer happens in last month of life

Cancer patients who have had end of life discussions cost 1/3 less to care for

Solving the Health Care Problem

The fundamental goal of health care is value for patients

$$\text{Value} = \frac{\text{Health outcomes that matter to patients}}{\text{Costs of delivering these outcomes}}$$

Value is created by managing a patient's medical condition over the full cycle of care

$$\text{Value} = \frac{\text{The set of outcomes that matter for the condition}}{\text{The total costs of delivering these outcomes over the full care cycle}}$$

In primary and preventative care value is created by serving segments of patients with similar primary and preventative needs

Creating Value-Based Health Care Delivery

A Mutually Reinforcing Strategic Agenda

Re-organize care around patient conditions, into integrated practice units (IPUs) or population segments

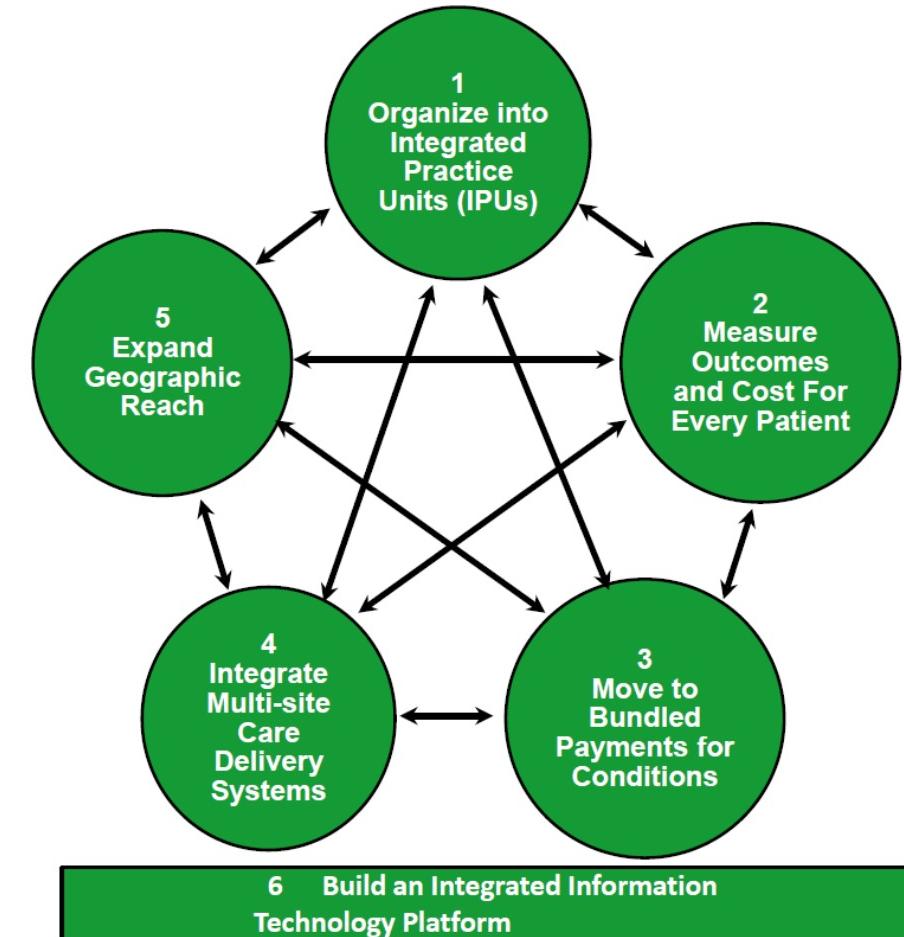
Measure outcomes and cost for every patient

Move to value-based reimbursement models and ultimately bundled payments for conditions and primary care segments

Integrate multi-site care delivery systems

Integrate care across geography to improve value

Build an enabling information technology platform



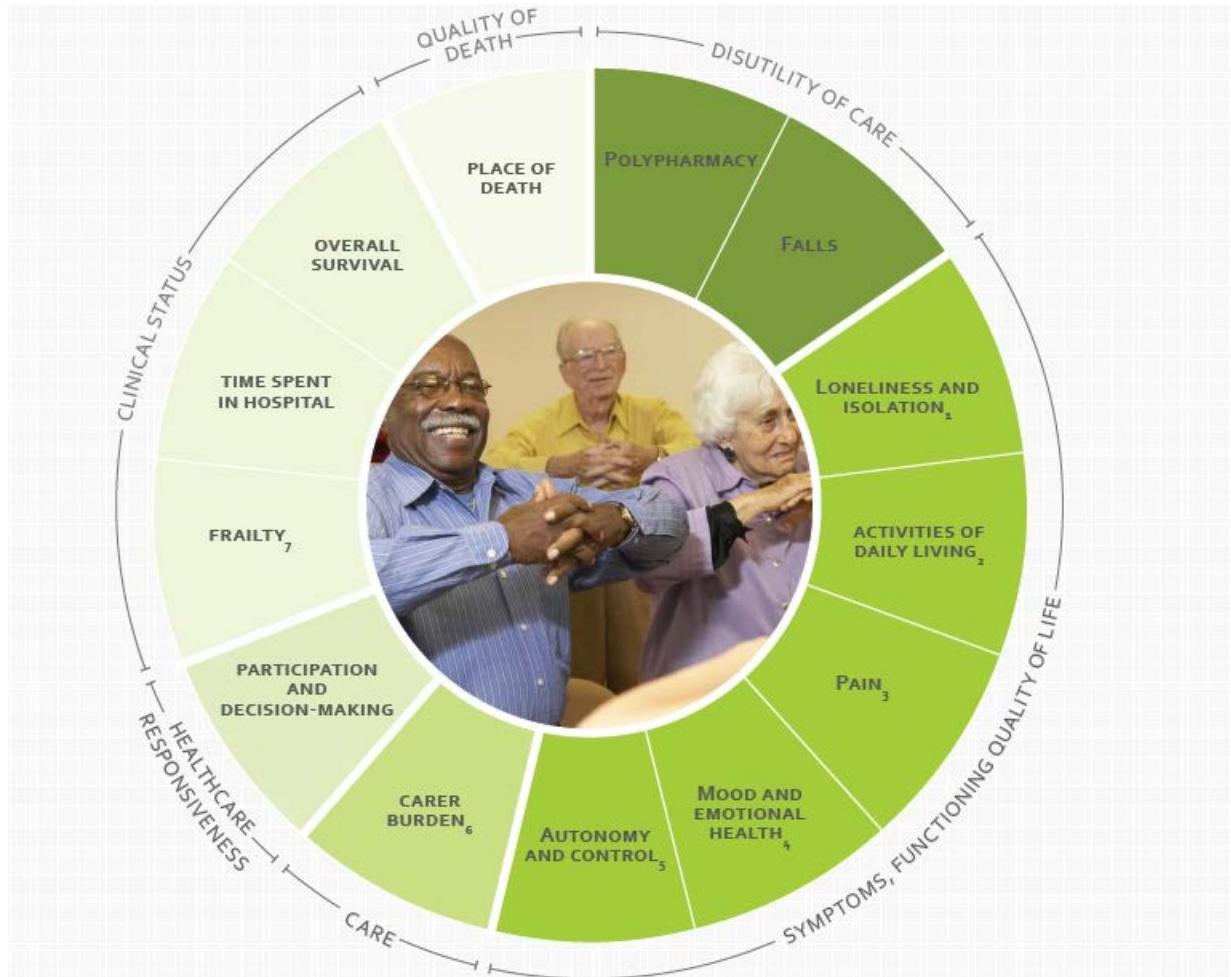
How Should We Assess Value in Advanced Illness?

$$\text{Value} = \frac{\text{Health outcomes that matter to patients}}{\text{Costs of delivering these outcomes}}$$

What are the outcomes that matter to patients with advanced illness?

What are the costs to achieve those outcomes in patients with advanced illness?

How Should Measure Outcomes in Advanced Illness?



Details

- ¹ Tracked via the UCLA 3-item Loneliness Scale
- ² Tracked via the 36-item Short Form Survey Instrument Version 1 (SF-36)
- ³ Tracked via the SF-36
- ⁴ Tracked via the SF-36
- ⁵ Tracked via the Adult Social Care Outcomes Toolkit
- ⁶ Tracked by the Zarit Burden Interview 4-item screening questionnaire
- ⁷ Tracked via the Canadian Study on Health & Aging Clinical Frailty Scale



ICHOM Measures for Elderly

Loneliness, mood

Time in hospital

Participation in decision making

Family care burden

Pain and suffering

Activities of daily living

Place of death

Place of Death

About 80% of Americans would prefer to die at home if possible but only if they are not a burden to the family

Currently only 20% die at home, 60% of die in hospitals and 20% in nursing homes

Doctors die in hospitals and ICUs less frequently than lawyers and the general population

A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life

80% of patients with chronic diseases want to avoid hospitalization and ICU when dying

Death Before the Era of Modern Medicine

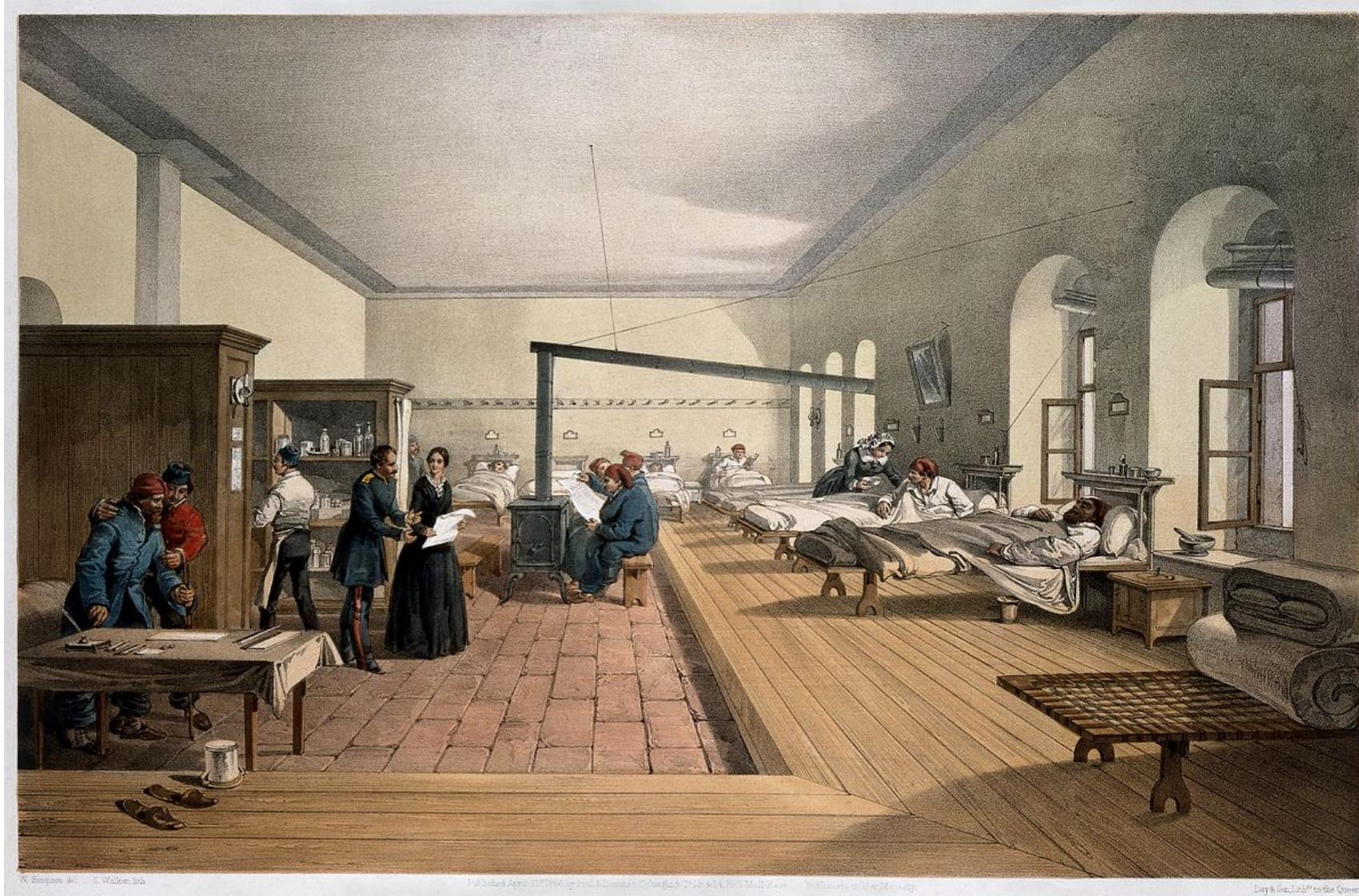


Henry Nelson
O'Neil
The Last
Moments of
Raphael
1866

abc-people.com

Beginning the Era of Modern Medicine

Florence
Nightingale
Hospital Ward
at Scutari



Death in the Era of Modern Medicine

Hospitals as places to die evolved to places to be cured

Intensive care units in the 20th century transformed dying

Life support for failing lungs, circulation, and kidneys created new set of problems

Death transformed to removal of life support requiring complex education of family units unfamiliar with nearly everything including the doctors and nurses providing the care

Hope in the Era of Modern Medicine

Boston
Children's
Hospital
cardiac
intensive
care unit.
2013



Death in the Era of Modern Medicine



Have we over medicalized death? Around 20% of all US deaths occur in or shortly after an ICU admission

The ICU in Modern Medicine

The commonest reason for ICU admission is respiratory failure

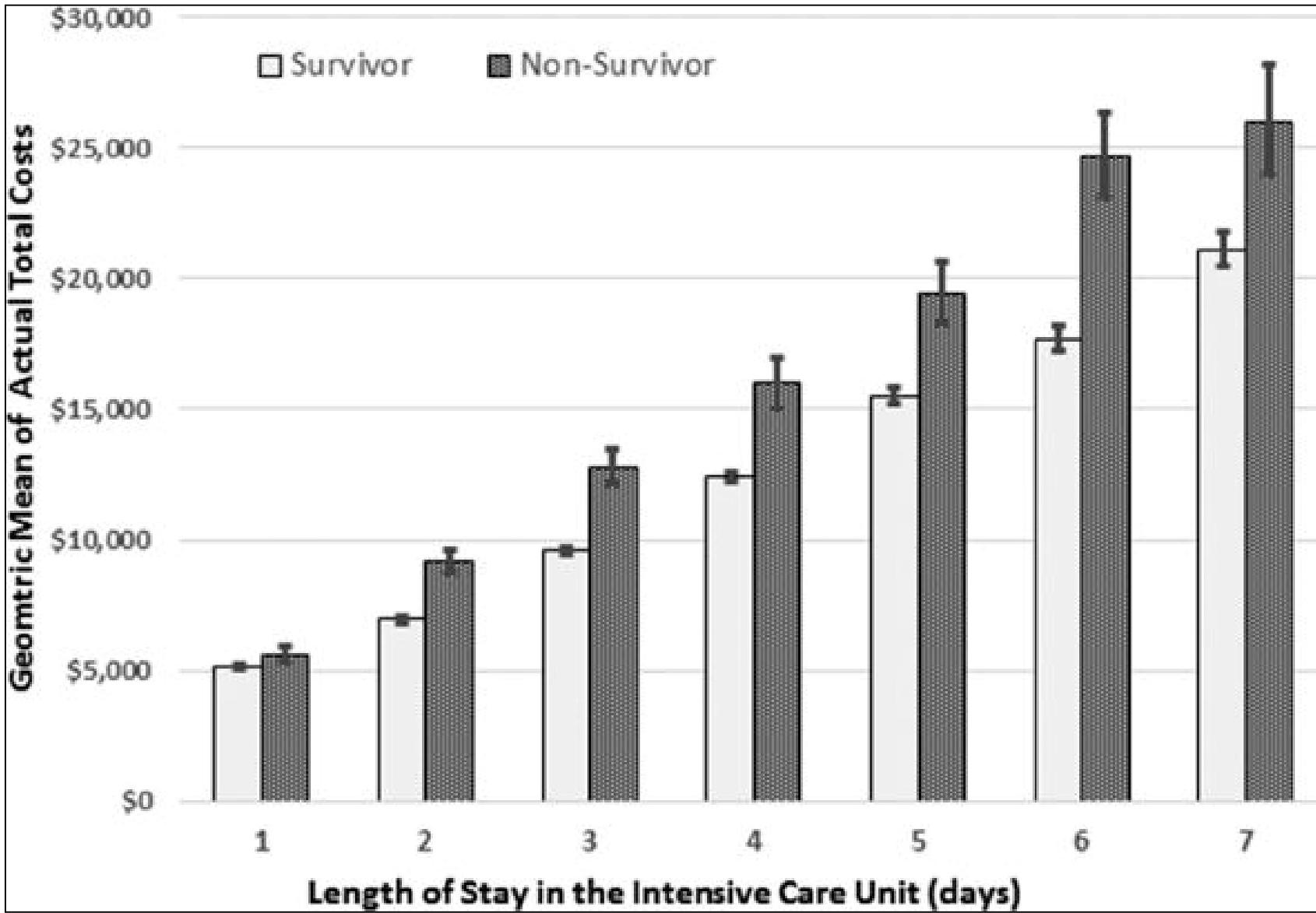
8 Percent of all US hospital beds are ICU beds

4 million annual admissions to US ICUs

Average ICU mortality is 10-20%

ICU patients occupy 5-10% of hospital beds but account for 20-35% of hospital charges

Death in the Era of Modern Medicine



Some Patient Examples

57 y.o. male with advanced lung cancer on chemotherapy develops heart failure and respiratory failure. Needs life support for breathing. No advanced directive.

72 y.o. female with advanced colon cancer suffers stroke due to a brain hemorrhage. Needs life support for breathing. Advanced directive in chart.

32 y.o. male in fire with 95% burns. Needs life support for breathing. No advanced directive.

Some Doctor Examples

When do you discuss death with cancer patients?

Oncologist A – for all patients with advanced cancer I point out that they will most likely die of their cancer but that we will keep you informed enough to make decisions about the goals of care as needed.

Oncologist B – Patients come here with hopes of being cured. My job is to support their hope. I cannot imagine telling a cancer patient who is enjoying rock climbing that they are going to die of their disease.

Oncologist C – I would love to have those conversations with my patients but I simply do not have enough time in my day to have those conversations and answer all the subsequent questions. Besides, I do not get reimbursed for that.

What needs to be done among the major influencers? Public – Patients and their Families

Before: Better public understanding of dying process

- Discuss goals of care with family and close friends when all is well

- Keep an updated advanced directive and anything about you that could help a team that does not know you

During: Ask for more information whenever something is not clear

- Ask for help when needed

- Rest, eat and sleep

- Be honest in representing the patient – it is their wishes not yours

After: Share your experiences with those who provided care

The Problem with Advanced Directives

Movement began with the enactment of the Patient Self Determination Act of 1990. Multiple successful campaigns.

Now while only 20-30% of all Americans have an advanced directive 72% of over 60s have one

Physicians are often unaware of the presence of an advanced directive or what it says. Only 25% of physicians were aware their patient had one.

Documents become misplaced when needed

Patient's instructions can be overridden

Since they are not medical orders they are actually vague and open to interpretation

What needs to be done among the major influencers? Practitioners and Administrators

Organize care around the multidisciplinary needs of these patients

Earlier conversations about end of life values with the patient

Include family as widely as possible to understand goals of care

Engage palliative care and supportive care professionals early

Encourage the use of advance directives and medical power of attorney

Update both documents regularly especially when health status is changing

Assign staff responsibility for managing end of life issues for patients in the practice

Utilize Physician Orders for Life Sustaining Treatment (POLST Forms)
whenever possible – initiatives now in 40 states

POLST Forms for Interventions

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY													
<p align="center">Physician Orders for Life-Sustaining Treatment (POLST)</p> <p>First follow these orders, then contact physician or NP. This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.</p>													
<input checked="" type="checkbox"/> Check One	<p>Last Name _____</p> <p>First Name/ Middle Initial _____</p> <p>Date of Birth _____</p>												
A <input checked="" type="checkbox"/> CARDIOPULMONARY RESUSCITATION(CPR): Person has no pulse and is not breathing. <input type="checkbox"/> Resuscitate/CPR <input type="checkbox"/> Do Not Attempt Resuscitation (DNR/no CPR) <p>When not in cardiopulmonary arrest, follow orders in B, C and D.</p>													
B <input checked="" type="checkbox"/> MEDICAL INTERVENTIONS: Person has pulse and/or is breathing. <p><input type="checkbox"/> Comfort Measures Only Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <i>Do not transfer to hospital for life-sustaining treatment.</i> <i>Transfer if comfort needs cannot be met in current location.</i></p> <p><input type="checkbox"/> Limited Additional Interventions Includes care described above. Use medical treatment, IV fluid and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. <i>Transfer to hospital if indicated. Avoid intensive care.</i></p> <p><input type="checkbox"/> Full Treatment Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <i>Transfer to hospital if indicated. Includes intensive care.</i></p> <p><i>Additional Orders:</i> _____</p>													
C <input checked="" type="checkbox"/> ANTIBIOTICS <p><input type="checkbox"/> No antibiotics. Use other measures to relieve symptoms. <input type="checkbox"/> Determine use or limitation of antibiotics when infection occurs. <input type="checkbox"/> Use antibiotics if life can be prolonged.</p> <p><i>Additional Orders:</i> _____</p>													
D <input checked="" type="checkbox"/> ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food by mouth if feasible. <p><input type="checkbox"/> No artificial nutrition by tube. <input type="checkbox"/> Defined trial period of artificial nutrition by tube. <input type="checkbox"/> Long-term artificial nutrition by tube.</p> <p><i>Additional Orders:</i> _____</p>													
E <p>SUMMARY OF MEDICAL CONDITION AND SIGNATURES</p> <table border="1"> <tr> <td>Discussed with:</td> <td colspan="2">Summary of Medical Condition</td> </tr> <tr> <td> <input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Health Care Representative <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Other: _____ </td> <td colspan="2"></td> </tr> <tr> <td>Print Physician/ Nurse Practitioner Name _____</td> <td>MDDO/NP Phone Number _____</td> <td>Office Use Only _____</td> </tr> <tr> <td>Physician/ NP Signature (mandatory) _____</td> <td>Date _____</td> <td></td> </tr> </table>	Discussed with:	Summary of Medical Condition		<input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Health Care Representative <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Other: _____			Print Physician/ Nurse Practitioner Name _____	MDDO/NP Phone Number _____	Office Use Only _____	Physician/ NP Signature (mandatory) _____	Date _____		
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Physician/ NP Signature (mandatory) _____	Date _____												

What needs to be done among the major influencers? Policy Makers

Strengthen the impact of advanced directives

Make interoperability a reality

Fund educational public awareness programs

Educate Medicare beneficiaries

What not to do?



What not to do?

Doctor on Video Screen Told a Man He Was Near Death, Leaving Relatives Aghast

By Julia Jacobs

March 9, 2019



A doctor on a video conference explained to Ernest Quintana that he did not have long to live. Mr. Quintana's family members criticized the use of telemedicine in that circumstance.

Additional Reading

U.S. Congress, Senate, Special Committee on Aging. Death with Dignity, An Inquiry into Related Public Health Issues: Hearings before the Special Committee on Aging. 92nd Congress 2nd session. August 7-9, 1972:3

Atul Gawande. Being Mortal: Medicine and What Matters in the End, 2014
End-of-Life Care Intensity for Physicians, Lawyers, and the General Population.
JAMA 2016 315:303-5

Death Before the Era of Modern Medicine

Thomas Rowlandson, Middlesex Hospital, from *The Microcosm of London* (1808). London Lives.

